



# THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

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This Tip Sheet offers guidance for involving family members in the work of mental health policy groups. It provides a definition of "family member" and briefly describes the context for family involvement in policy group work. It contains strategies for recruiting family members to join policy groups, training and supporting family members to do the work, and sustaining their participation over time.

## *Involving Families in Policy Group Work*

### Definition of Family Member

A child's family is the group of individuals who support that child - emotionally, physically, and financially. It can include individuals of various ages who are biologically related, related by marriage, or not related at all.

A family unconditionally provides love, guidance, care, support, and otherwise nurtures all members, especially its children. Each family has a culture of its own - in addition to the external cultures it affiliates with. This influences how the family approaches the tasks of daily living (food, dress, work, school) and can direct how a family faces the challenges of raising a child with mental health needs. Families work in different ways and have different resources at their disposal.

### Context

Mental health policy groups are made up of individuals who are expected to speak with authority and make recommendations based on their experience and knowledge. Many mental health policy groups, such as State Mental Health Planning & Advisory Councils, are required to include family members of children who are served by the agency or program.

Policy Groups leaders work hard to maintain continuity, cohesion, and focus in the face of changing membership (family and others) and shifts in the political climate or economic environment. Bringing new members on board and up to speed is an ongoing activity.

Family members contribute integrity to policy group work by providing reality-based, culturally relevant information from a perspective that no one else has. Yet, policy group leaders struggle to find family members who are willing and able to make such a commitment and sustain their involvement over time.

### Recruiting Family Members for Policy Groups

States and their Mental Health Policy Groups can reach out to families in a variety of ways. Indirect methods for reaching families include contacting existing state and local agencies, groups or associations that support the mission of the policy group. Examples of this approach include family organizations like chapters of the Federation of Families for Children's Mental Health, parent support groups, mental health providers, children's mental health advocacy organizations, and schools. More direct methods for establishing connections with families include sponsoring and/or attending conferences, forums or public discussions

concerning children's mental health. Hosting public gatherings that create awareness of the policy group's purpose and achievements can also attract families.

Once a link has been established with families, a representative of the policy group should meet with them to:

- Explore common hopes and concern
- Explain the purpose of the policy group
- Share the group's accomplishments
- Discuss the family's interest in being involved
- Ask what they will need in order to participate
- Accept the level of involvement that families can offer
- Understanding how the group operates is essential. Families must know what the structure is and how decisions are made. Answers to the following questions will help families decide if they want to participate:
  - Does the policy group focus solely on children's issues, or is there a sub-committee of the group responsible for children and youth?
  - What is the authority of the group and its committees?
  - Does the group have by-laws and are they enforced?
  - What are the requirements for membership?
  - What is the composition of the group?
  - How much influence does the group have?
  - When and where does the group meet?
  - How much time commitment, beyond attending meetings, is expected to prepare for meetings or attend to committee assignments?

Families & family organizations do not need to wait to be approached by policy groups. Just as policy groups are seeking family involvement, families and family organizations are looking for the opportunity to effectively participate in policy work. Family-run organizations that successfully seek out and reach out to policy groups advise the following.

- Get to know the mental health authority & make an appointment; ask questions; explore how you can be involved in existing opportunities; send a note of appreciation after your visit.

- Ask for and read your state's plans for agencies that serve children with mental health needs & ask questions about sections you don't understand.
- Know the responsibilities of the policy group.
- Learn who the members of the policy group are and what their background is & meet with any of them individually or attend a meeting and learn about their priorities.
- Find out when and where policy groups meet and attend as an observer.
- Ask about the current focus of their work.
- Learn how the group operates.
- Follow through with commitments.

In addition to establishing relationships with policy groups, it is vital for family organizations to know the realities of the environment in which the work is done. Internal and external factors (such as personal agendas, turf issues, systems crisis or litigation) can have impact upon how the policy group selects priority issues and makes decisions. Family organizations can become more aware of the environment by:

- Staying connected with the network of a family organization.
- Developing common agendas with others.
- Creating strategic alliances.
- Maintaining integrity to their mission.

## **Training and Supporting Family Members on Policy Groups**

Policy groups that have access to flexible, tangible and practical resources are better prepared to meet the individual needs of their family members. Training for family representatives is essential for them to effectively participate in policy activities. Training group members in working collaboratively with families is equally essential.

While the personal experiences of family members are critically informative at policy tables, it is challenging for family representatives to present their stories and keep any distressing accompanying emotions (fear, anxiety, humiliation, anger, frustration, distrust and disappointment with the service system) in check. Family members and other policy group members can significantly benefit from training in how to reframe

personal experiences to reveal the underlying systems issues. Family members and family-run organizations that have system experience can best provide such training. There are other important ways of making sure family members consistently and effectively participate on policy groups.

## **Select meeting times and locations that support attendance**

Families of children and youth with mental health issues have demanding schedules. Check with family members' schedules before finalizing policy group meeting times and locations. Providing a light meal or childcare can also make it easier for family members to attend daytime meetings.

Policy groups should be flexible and creative in finding meetings times that accommodate family scheduling needs. Some options are to meet in the evening or on weekends or patch families in by conference call. Consider using distance-learning technologies such as computers or video and satellite conferencing facilities that may be available at colleges and universities to allow families in remote parts of the state to participate.

## **Recruit more than one family representative**

It is a heavy burden for one family member to represent all the families in a community or state. Having a diverse group of peers to work with on a policy group is very appealing to family members because it insures them that the diversity of family experiences, cultures, backgrounds, and perspectives will have a voice at the table and that there is "back-up" if an emergency keeps them from attending a meeting. This will also help prevent feelings of "tokenism" and provide a friendly environment for new families who join. Give families opportunities and supports to meet one another prior to the meeting if they wish. Policy groups will benefit substantially from the informal orientation and mentoring that result from families connecting with one another.

## **Supply flexible financial support**

Many families cannot afford the ancillary expenses of joining a policy group. Stipends and reimbursements for dependent care, transportation (airline, buses, or

other public means, tolls, mileage, etc.), lodging (if necessary) and meals can make a critical difference for family members. Policy groups that arrange travel, provide cash per diems in advance and master bill hotel rooms for national meetings reduce the financial burden and stress on family members attending events requiring that they be away from home. Agencies that administer funds for policy groups need methods for timely (immediate) reimbursement of out-of-pocket expenses born by family members. Arranging for cash reimbursement at the meeting makes it possible for family members to attend and participate when they don't have credit cards or checking accounts.

## **Provide access to communication**

Just as other policy group members use cell phones and pagers to communicate with staff, co-workers or their families, family members have to respond to the immediate needs of their children, schools, daycare or work. Practices that can help family members keep in touch with home include:

- Letting group members know the incoming phone numbers ahead of time so they can leave this information with their families.
- Providing phone cards for long distance calls and making sure there are pay phones available for families
- Having a cell or regular phone at the meeting registration desk to receive emergency calls
- Scheduling phone breaks during the meeting
- Family members can help their policy groups by clearly explaining their communication needs in advance and being responsible about using the resources they are given.

## **Share Information**

Family members at the policy table have a responsibility to represent their constituency's needs and not just their own personal agenda. When taking a position or presenting a perspective they should be prepared to explain where the information came from and what process was used to get it. Legitimate data sources include (but are not limited to) formal reports, focus groups, surveys, support group discussions. Policy groups should feel free to seek additional information from family organizations that reach out to numerous families; and also to seek substantiating data.

Policy groups should make it easy for family members who have new and relevant information to get it copied and distributed to others. Policy groups should build funds for these expenses into their budgets. The actual copying can be done by a local copying and printing business, be assigned to the support staff for the group; or be handled by the (or other) agency sponsoring the policy group.

Policy groups, in turn, should make sure that family members are well informed of the issues the group is discussing. However, family members do not want to be overwhelmed by too much information. Some may be reluctant to ask for help interpreting background materials or proposals for discussion. Offering a clear explanation of what is being worked on (including budgets) and how it relates to the bigger picture will help family members feel comfortable, confident, and competent to make informed decisions. Pairing family members, especially newer members, with more experienced members of the group is an effective strategy for reviewing materials before meetings take place.

## **Provide validation & appreciation**

Family members on policy groups want to know that their input is valued. Other families in the community need to see how their representative's contributions are being used. Publishing meeting minutes creates a formal record of group activities, the results of any follow up on their actions and documents the role that members played in making recommendations and decisions.

## **Sustaining Family Involvement on Policy Groups**

Maintaining a full and diverse complement of members is essential for the ability of mental health policy groups to make fully informed, publicly responsible decisions. Having valid information and consistent communication reduces the confusion and frustration that may result in loss of members. Mental health authorities can assist by providing sufficient and consistent staff support and resources for policy group activities. State and local agencies can contribute to group stability by having incoming staff representatives attend a meeting with their exiting predecessor.

Families who have the supports necessary for coping with turmoil or confusion in their daily lives are better equipped to follow through with commitments to policy groups. Agencies sponsoring policy groups should make every effort to help family representatives stay connected to appropriate providers so their children can continue to receive all essential mental and physical health services and supports, educational services, child care and family supports.

Group members all need a sense of purpose, acceptance and accomplishment. Policy groups that are successful at sustaining family involvement have clearly defined mission, purposes, policies, operational procedures (by-laws in some cases), responsibilities, lines of authority and accountability, and reliable clerical and administrative support for communication and logistics. They hold meetings consistently and efficiently conduct them in a manner that is respectful, safe and supportive for all members. Successful policy groups have effective leadership that all members recognize as legitimate and they express their appreciation for the work of their members.

Data and the ability to understand its implications are key to making appropriate policy recommendations, preserving precious resources, achieving intended outcomes, and promoting necessary change. Policy groups that are successful in sustaining family involvement make sure that all members have access to the same information in a format and language that is universally understandable and free of jargon, complicated technical terms, or acronyms. Technology can assist in keeping members up to date with accurate and timely information. Strategic planning accompanied by training and technical assistance for all policy group members helps to foster collaborative working relationships.

## **Where to Get More Information**

For more information and training on strategies for engaging families in policy work contact the

- **Federation of Families for Children's Mental Health**, 1101 King Street, Suite 420, Alexandria, VA 22314, (703) 684-7710 [www.ffcmh.org](http://www.ffcmh.org);
- **National Council on Family Relations**, 3989 Central Ave. NE, #550, Minneapolis, MN 55421, (763) 781-9331 [www.ncfr.org](http://www.ncfr.org)

- **National Association of Mental Health Planning and Advisory Councils**, 1021 Prince Street, Alexandria, VA 22314, (703) 838-7522 [www.namhpac.org](http://www.namhpac.org).

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